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Descriptors of Breathlessness in Children With Persistent Asthma

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Background: **In adult patients, the consistent use of language to describe dyspnea enhances patient-provider communication and contributes to diagnostic and therapeutic decisions. The objective of this research was to determine whether pediatric patients similarly display consistency in the language used to describe "uncomfortable awareness of breathing."**

Methods: **One hundred children between the ages of 8 and 15 years with moderate to severe persistent asthma enrolled in an asthma education research program completed questionnaires regarding descriptors of asthma on each of two occasions. In addition to the breathlessness questionnaires, demographic information, self-reported asthma severity, ED visits, missed school days, anthropometrics, and spirometry were obtained for each participant.**

Results: **Children were reliable in their choice of the descriptors that they applied to their breathing discomfort across two occasions, and they selected the same descriptors that were used by adults with asthma in previous studies. Children with greater self-reported asthma severity endorsed more descriptors to characterize breathing discomfort than did children with less severe asthma, but no differences were found among children based on demographic or anthropometric variables.**

Conclusions: **Children with moderate to severe persistent asthma are reliable in their choice of descriptors of breathlessness. Knowledge of their experience of symptoms may be helpful clinically in the assessment and management of asthma.** ***CHEST 2011; 139(4):832–838***

Dyspnea, or breathlessness, is used to characterize a subjective experience of breathing discomfort that is composed of qualitatively distinct sensations that vary in intensity.[1] It is a common symptom in patients with respiratory and cardiovascular diseases, and a cause of morbidity in the elderly.[2] Dyspnea varies along several dimensions, including intensity and salience, and can include cognitive and emotional components.[3] As such, it is a complex sensory experience, derived from physiologic conditions that both influence and are influenced by psychologic processes and social variables.[1-4]

The terms used to describe dyspnea have been developed and studied extensively in both laboratory and clinical settings.[5-9] These studies have included: asking adults to select items from standardized questionnaires; identifying, by cluster analysis, descriptor groupings (clusters) that are independent of one another; and relating clusters with physiologic elements of disease. The work has shown that descriptor clusters are fairly consistent among patients with a disease but vary between patients with different disorders. Patients with asthma, for example, are likely to endorse the questionnaire items "My chest feels tight"

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(from the cluster labeled "Tight") and "I cannot get enough air in" (from the cluster labeled "Work/effort") to characterize their breathlessness, but patients with interstitial lung disease tend to select "My breathing is rapid" (from the cluster labeled "Rapid").[7] Additionally, some clusters (eg, "Work/effort") are endorsed by patients diagnosed with a variety of disorders. Together, these findings suggest that dyspnea is experienced in different ways depending on underlying physiologic conditions.[7-12]

Analysis of the language of dyspnea may facilitate patient-provider communication, assist in identification of a specific diagnosis, and help evaluate the symptomatic benefit of a therapeutic intervention.[7,10,12,13] Few investigations have considered the experience of breathlessness in children,[14] and none has evaluated responses obtained on standardized questionnaires. The primary objective of this investigation, therefore, was to examine descriptors of breathlessness used by children. Because asthma is a condition that afflicts both children and adults we studied descriptors of breathlessness in pediatric asthma patients.

Materials and Methods

Research Setting and Participants

The sample was drawn from children enrolled in a pediatric asthma education research program (Project On TRAC: Taking Responsibility for Asthma Control). Program participants were between 8 and 15 years of age, had been diagnosed with asthma for a minimum of 2 years, used controller medications daily, and reported at least occasional asthma symptoms and/or nighttime cough. Children and their families were advised about all aspects of the research protocol. Each child's legal guardian provided written informed consent, and the child provided written informed assent during an initial intake session. The institutional review boards at both the University of North Carolina at Charlotte (#09-09-03) and Ohio University (#03F024) approved the project protocol. The patients included in this report were the first 100 children enrolled in the program that provided information about terms they use to describe their dyspnea on two occasions.

Procedure

Dyspnea was characterized by the items of a breathlessness questionnaire.[6-8] The questionnaire (Table 1) consisted of 15 different statements. We administered the questionnaire on two predetermined occasions during the asthma education research program; the average time between events was approximately 7.5 weeks (53.2 ± 14.1 days). At each administration of the questionnaire the patient was randomly given one of four different forms of the questionnaire that differed only in the order in which the 15 statements were listed on the page. Patients were instructed to select "Yes" or "No" if the statement described their "uncomfortable awareness of breathing" with asthma. If patients responded "Yes" to more than three statements, they also were asked to pick the "best three" descriptors that applied to their breathing difficulty.

Self-reported asthma experiences were rated by children for overall asthma severity (from mild [1] to severe [5]), for levels of asthma management (from very well managed [1] to not managed at all [5]), and for asthma bother (from hardly noticeable [1] to very troublesome [5]). Demographic information was also collected for each child. FVC and FEV_1 were measured in the standing position using the VMAX ENCORE 20C testing system (VIASYS Healthcare; Yorba Linda, California).

Data Analysis

We conducted tests for differences in binomial probabilities to determine whether participants' endorsement of descriptors differed significantly from chance at each administration using adjusted *P* values for multiple comparisons using the Holm method.[15] We used paired *t* tests to compare the number of descriptors endorsed at each administration, and *t* tests for independent groups to compare the descriptors endorsed by participant subgroups. The best three descriptors selected by children were compared with those selected by adults in earlier studies. Data points were entered into our statistical program (SPSS version 13.0; SPSS Inc; Chicago, Illinois) and checked for discrepancies.

Results

Participants

Children ranged in age between 8 and 14 years (mean ± SD, 10.21 ± 1.5) and had been diagnosed with asthma for 6.9 ± 2.7 years. Other descriptive information is summarized in Table 2.

Overall Selection of Descriptors

The children selected 8.9 ± 3.1 descriptors on the first administration of the questionnaire and 7.4 ± 3.9 descriptors on the second. The decrease between administrations was statistically reliable (t [99] = 4.17, $P < 0.001$). Three descriptors ("My chest feels tight," "I feel out of breath," and "My breathing is heavy") were selected consistently, on both occasions, at a rate greater than chance. Seventy-nine percent of the children selected at least one of these descriptors on both testing occasions ($P = 0.05$), and 60% of children selected at least two ($P = 0.057$). Many descriptors were selected on both occasions at a chance level; others were selected at a rate less than chance. The percentage of participants who selected each dyspnea descriptor on both administrations of the questionnaire is presented in Table 3.

We compared the total number of descriptors selected by several subgroups of children. Differences in the number of descriptors selected were not observed: between children ≤ 10 years of age (n = 57) and those ≥ 11 years of age (n = 43), between children who had been diagnosed with asthma for ≤ 7 years (n = 51) and those diagnosed for ≥ 8 years (n = 47), between boys (n = 68) and girls (n = 32), between whites (n = 50) and blacks (n = 42), or between those below the 50th percentile for BMI (n = 53) and those at or above the 50th percentile (n = 47). On the other

Table 1—*Questionnaire Composed of Descriptors of Breathlessness*

1. My breath does not go in all the way.
2. My breathing requires effort.
3. I feel that I am smothering.
4. I feel hunger for air.
5. My breathing is heavy.
6. I feel out of breath.
7. My chest feels tight.
8. My breathing requires work.
9. I feel that I am suffocating.
10. My chest is constricted.
11. I feel that my breathing is rapid.
12. My breathing is shallow.
13. I feel that I am breathing more.
14. I cannot get enough air.
15. My breath does not go out all the way.

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hand, children who rated their asthma as moderate to severe or severe (n = 43) selected a significantly greater number of overall descriptors on both the first (mean = 9.9) and second (mean = 8.8) administration of the questionnaire than did children (n = 56) who rated their asthma as mild, mild to moderate, or moderate (mean = 8.0 and 6.3, respectively; t (97) = −3.29, $P < 0.001$ and t (97) = −3.29, $P < 0.001$).

We also compared whether demographic and disease variables were related to the most frequently endorsed descriptors (Table 3). The rate at which the descriptor "My chest feels tight" was selected did not vary reliably by age, gender, race, BMI, or self-reported asthma severity; and the rate at which the descriptors "I feel out of breath" and "My breathing is heavy" were selected also did not vary reliably by gender, race, or BMI. "Out of breath" was selected more frequently on the second occasion significantly more often in children who were older ($P < .008$); and "heavy" was selected more frequently on both the first ($P < .008$) and second administration ($P < .01$) more often in children who rated their asthma as less well managed compared with those who rated their asthma as "well managed" or "very well managed." The details of these observations are shown in Table 4. In equivalent analyses, no reliable differences were observed in the rate at which the descriptors "My chest feels tight," "I feel out of breath," or "My breathing is heavy" were selected between patients based on lung function, ED visits for asthma the previous 12 months, or school days missed due to asthma the past year.

Table 2—*Characteristics of Participants (N = 100)*

Variable	Mean ± SD
Age, y	10.21 ± 1.5
Age at asthma diagnosis, y	3.28 ± 2.5
School missed the previous 12 mo due to asthma, d	4.69 ± 6.5
ED visits for asthma the previous 12 mo, No.	0.98 ± 2.2
Self-reported asthma severity[a]	
Severity	2.44 ± 1.2
Managed	2.60 ± 1.1
Troublesome	2.80 ± 1.1
Anthropometrics	
Height, cm	146.2 ± 13.1
Weight, kg	46.8 ± 19.9
BMI	21.2 ± 6.1
Lung function	
FEV_1, L	1.9 ± 0.6
FEV_1, % predicted	85.5 ± 17.8
FVC, L	2.3 ± 0.7
FVC, % predicted	89.6 ± 15.5
FEV_1/FVC	83.2 ± 10.4

[a]Asthma severity was rated from mild (1) to severe (5), from very well managed (1) to not managed at all (5), and from hardly noticeable (1) to very troublesome (5).

Best Three Descriptors

In previous research, the 15 descriptors listed in Table 1 reduced to 10 unique groupings, or clusters, of descriptors.[7,8] In Table 5 we present the best three descriptors obtained previously in adult patients for three conditions, including asthma, for comparative purposes.

Children selected a small number of descriptors as one of the best three on both administrations of the questionnaire (Table 6). Pediatric patients selected these descriptors with a high degree of consistency: 81% of children selected at least one of these descriptors on both occasions ($P = .01$), and 58% of children selected at least two of these descriptors on both administrations of the questionnaire ($P = .13$). As in adults with asthma, two terms consistently chosen by children to describe their dyspnea were "My chest feels tight" (cluster "Tight") and "I cannot get enough air in" (cluster "Work/effort"). "I feel out of breath" (cluster "Work/effort") was a descriptor also frequently selected by pediatric patients with asthma on both administrations of the questionnaire.

Discussion

Dyspnea is a common experience in patients with respiratory and cardiovascular diseases and those with cancer, those in hospice care, and the elderly.[2,16,17] Efforts to study breathlessness are evident in research extending back at least several decades, including the work of Kinsman and colleagues[18] who derived a 77-item Asthma Symptom Checklist to measure symptoms of acute asthma in adult patients. We have demonstrated that unpleasant sensations that arise from asthma can be investigated reliably in patients as young as 8 years of age using a 15-item questionnaire.

Table 3—*Percentage of Patients Selecting Each Descriptor at the Two Questionnaire Administrations*

Descriptor	Time 1, %	Time 2, %
My chest feels tight.	84[a]	67[a]
I feel out of breath.	77[a]	70[a]
My breathing is heavy.	73[a]	61[a]
I cannot get enough air.	76[a]	59
My breathing requires work.	73[a]	54
My chest feels constricted.	67[a]	54
My breathing requires effort.	64[a]	57
My breath does not go in all the way.	57	50
I feel hunger for air.	55	42
My breathing is shallow.	53	43
I feel that my breathing is rapid.	58	39[b]
I feel I am breathing more.	46	39[b]
My breath does not go out all the way.	38[b]	42
I feel that I am smothering.	36[b]	31[b]
I feel that I am suffocating.	35[b]	30[b]

[a]Descriptor selected at a rate greater than what would be expected by chance.

[b]Descriptor selected at a rate less than what would be expected by chance.

Children with asthma consistently used the same terms to describe their dyspnea on tests separated by about 2 months. Out of 15 terms, they endorsed only three reliably on both testing occasions: "My chest feels tight," "I cannot get enough air in," and "I feel out of breath." Most children selected at least one of the terms to describe dyspnea on each of the two testing occasions. The children also systematically avoided using some descriptors. Overall, these analyses showed consistency in describing dyspnea not only within subjects but also between subjects and supported the hypothesis that breathlessness is experienced in a specific way among children with asthma.

A possible objection to this hypothesis is that some portion of the variability in children's perception of asthma may have been determined by factors not characteristic of the disease itself. We examined this question by relating demographic and severity variables to selected descriptors. Children who perceived their asthma as more severe selected a greater number of descriptors than those who rated their asthma as less severe. Otherwise, children's descriptions of their dyspnea did not differ by age, asthma duration, gender, race, and BMI or by severity variables, including self-reported asthma severity and asthma troublesomeness. From these various findings we concluded that the descriptors used by the children were characteristic of asthma rather than of qualities of individual patients.

The only exception to this conclusion was that well-managed children described their breathing as "heavy" less frequently than did children who were not well managed both in the first and in the second session. Additionally, "My breathing is heavy" was endorsed in the first session as one of the best descriptors. We reasoned that less-frequent selection of "heavy" in session two could be related to acquisition of asthma self-management skills as participants advanced through an asthma education program. It is also possible that selection of the term "heavy" is related more to instances of deconditioning than to asthma.[19] Compared with the general population, patients with asthma do not participate in routine exercise sufficient to meet national guidelines,[20] consistent with the observation that patients limited by exercise-induced asthma were in reality experiencing poor fitness.[21] In a related observation, von Leupoldt and colleagues[22] showed that verbal descriptors of dyspnea in patients with COPD enrolled in pulmonary rehabilitation were related to the intensity level of dyspnea and that descriptors of "heavy/fast breathing" were sensitive descriptors of dyspnea during exercise. How changes in behaviors such as exercise or activity levels affect language in children deserves additional attention.

Our finding that race had no effect on descriptive language is not consistent with all earlier work. Some investigators have found that whites and blacks differ

Table 4—*Percentage of Participants (N = 100) Who Chose the Three Most Frequently Selected Descriptors at the Two Test Administrations by Selected Variables*

Administration/ Descriptor	Age, y		Duration, y		Gender		Race		BMI		Severity		Managed		Troublesome	
	< 11	≥ 11	< 8	≥ 8	M	F	W	B	< 50th	≥ 50th	Mild	> Mild	Less	More	Low	High
First/chest tight	84	84	80	89	82	88	84	88	81	87	79	91	83	84	78	88
Second/chest tight	70	63	69	66	71	59	72	67	70	64	68	65	70	62	61	71
First/out of breath	74	81	69	85	75	81	74	79	77	77	70	86	82	71	66	85
Second/out of breath	60[a]	84[a]	63	79	68	75	72	69	66	75	63	79	76	62	56	79
First/heavy	72	74	71	77	74	72	70	79	68	79	75	70	83[a]	60[a]	63	79
Second/heavy	56	67	53	72	63	56	64	60	62	60	59	65	76[a]	44[a]	49	71

Variables: age, history of asthma (duration), gender, race, BMI, and self-reported asthma severity (severity, managed, and troublesome; see also Table 1). B = black; F = female; M = male; W = white.

[a]For each selected variable, observed values within each pair differ significantly from expected values.

Table 5—*The "Best Three" Descriptors Selected by Patients Arranged by Clusters*

Descriptor	Cluster
Chronic obstructive pulmonary disease (n = 85)	
My breathing requires effort (51%)	Work/effort
I feel out of breath (49%)	Work/effort
I cannot get enough air in (38%)	Work/effort
Asthma (n = 56)	
I cannot get enough air in (50%)	Work/effort
My chest feels tight (41%)	Tight
My breathing requires effort (29%)	Work/effort
Interstitial lung disease (n = 37)	
I feel out of breath (54%)	Work/effort
My breathing requires effort (35%)	Work/effort
My breathing is rapid (30%)	Rapid
I cannot get enough air in (30%)	Work/effort

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in the language they use to describe asthma,[23,24] whereas others have found variability in descriptors of symptoms and disease severity in black patients.[25] It is likely that outcome differences are due to methodologic differences, including patient variables, such as age, asthma severity, and medication usage; procedural details, including methacholine challenge during testing; and degree of structure imposed on the descriptor choices patients were allowed to make. Another factor is the willingness of patients to talk about their asthma. Adult blacks with asthma, for example, were generally less likely to complain of dyspnea than whites.[26] Considered as a group, these observations and some others[27] highlight our meager knowledge of ethnic differences in language used to describe dyspnea and preclude strong conclusions on the subject.

By itself, knowledge of how children describe their asthma symptoms tells us relatively little about how asthma is experienced throughout the general population. This challenge may be approached, however, by examining the degree of between-subject consistency in descriptions of symptoms in diverse groups that encompass a range of subpopulations. We addressed the consistency question by comparing the asthma descriptors children used in our study with those used by adults.[7] We noted a considerable degree of similarity in the way the two populations described asthma. Two descriptors, "My chest feels tight" and "I cannot get enough air in," were among those most frequently selected by children during both administrations of the questionnaire and were the two most frequently selected descriptors by adults previously.[28] The descriptor "My breathing requires effort" was ranked by children in this study and by adults in the earlier research. This degree of consistency demonstrated that despite age, the experience of asthma includes elements of chest tightness and effortful breathing.

Limitations of this study included a potential curb on generalization of our results to other samples of pediatric patients with asthma and on reliance of a restricted view of dyspnea. First, we did not study the language of children <8 years of age. Second, we studied children who were diagnosed with persistent, moderate to severe asthma 7 years earlier. It is possible that our results do not generalize to newly diagnosed children or to children whose asthma is mild. Third, the experience of dyspnea, like pain, is composed of multiple dimensions involving sensory quality, sensory intensity, unpleasantness, and emotional impact.[29] Our exploration of the qualities of experience in children focused on sensations of breathing discomfort, not on the "signs" of asthma (eg, wheezing, cough, or lung function), the intensity of breathing discomfort, or affective variables. Consideration of dyspnea broader than that limited to breathing discomfort might provide a view of language somewhat different from the one we have endorsed. Some work related to this possibility is already underway.[30] Studies conducted mostly with patients with COPD have shown that "breathing distress" or "dyspnea-related anxiety" can be measured separately and reliably.[31,32] In other work, a new measure has been developed to provide a score of breathlessness severity incorporating both physical and affective dimensions of breathing discomfort.[33] Such a score provides a multidimensional metric of breathlessness

Table 6—*Percentage of Patients Who Selected the Descriptor as One of the "Best Three" Terms Characterizing "Uncomfortable Awareness of Breathing" and Associated Cluster at the First and Second Questionnaire Administration*

First		Second	
Descriptor	Cluster	Descriptor	Cluster
My chest feels tight (59%)	Tight	My chest feels tight (39%)	Tight
I cannot get enough air in (36%)	Work/effort	I feel out of breath (33%)	Work/effort
I feel out of breath (30%)	Work/effort	My breathing requires effort (26%)	Work/effort
My breathing is heavy (30%)	Heavy	I cannot get enough air in (25%)	Work/effort

that that may be used to evaluate the overall severity of dyspnea not only within patient groups but also between different disorders.

Despite these limitations, research based on a standard inventory of descriptors may be useful for improving communication in the health-care setting. A standard inventory could reduce language differences between groups[14,34,35] and clarify poorly expressed or inconsistent complaints. Such a tool is an interesting possibility, but caution is advised as not all earlier work would support the distinctiveness of standard lists. Williams and colleagues[36] found they could distinguish between adult COPD and non-COPD groups on the basis of descriptors either volunteered by research participants or taken from a list identical to that used in this research. In view of the differences in age and type of disease between the present study and that of Williams and colleagues,[36] it would be worth the effort to determine whether use of a standardized inventory improves or clarifies communication among patients, families, and health-care professionals.

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Dr Harver: contributed to drafting initial versions of the manuscript.
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